TEXAS DEPARTMENT OF HEALTH
BUREAU OF HIV AND STD PREVENTION

Unique Identifier Reporting for HIV Infection Surveillance

November, 1997

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Introduction

During the past three years, the nature of the HIV epidemic has drastically changed in the United States. New therapies that, for many people, appear to successfully retard disease progression and improve health status, have been widely prescribed. These drugs do not appear to work for everyone, and in some the benefits are not permanent, but new drugs which show great promise are quickly being developed. These and other environmental changes have prompted the Bureau of HIV and STD Prevention of the Texas Department of Health (TDH) to conduct a thorough analysis of the effectiveness and efficiency of our current HIV disease reporting and follow-up systems, including how well they will be able to meet the new challenges posed by HIV and other sexually transmitted diseases (STDs) in the near future.

As a result of this analysis, we have concluded that our current HIV reporting system will not serve either our communities or individual citizens well over the next few years. The need is critical to make changes now to improve our ability to monitor the epidemic and to link clients with needed care, treatment and prevention services. Without these changes, our public's health will suffer. Additionally, Texas will be in an increasingly poor position to compete for ever-scarcer resources.

This paper details the need for HIV infection reporting, the reasons AIDS case reporting alone is not adequate, and an assessment of Texas' current Unique Identifier (UI) HIV reporting system.

Background: National HIV/AIDS Case Reporting

The Historic Focus on AIDS Reporting Rather than HIV Infection Reporting: Why?

Historically, surveillance for HIV disease has been tied to the onset of late-stage infection markers (AIDS). In 1982, the Centers for Disease Control and Prevention (CDC) published the first definition of AIDS to provide for surveillance of the syndrome identified a year earlier. That definition focused on conditions epidemiologically linked to related cases and did not include the full spectrum of HIV manifestations. In the absence of a reliable, inexpensive test for what was then only recognized as AIDS, this definition was the best tool for incidence monitoring. A national reporting system was put in place and all states adopted this surveillance case definition.

Changes to the original AIDS surveillance case definition have reflected increased knowledge of HIV-related illnesses. As experts gained a greater understanding of the underlying mechanisms of disease development, the AIDS case definition and focus of disease surveillance shifted from tracking diagnoses of opportunistic infections (1982 case definition) to using laboratory evidence

of severe immunosuppression (CD4+ below 200 microliters per decaliter of blood) as a marker of the beginning of AIDS (1993 case definition).

Along with the evolution of the AIDS case definition came a broader understanding of the role that HIV played in the development of AIDS. Experts understood that the public health concern relating to this epidemic was in fact infection with HIV. This broader understanding, coupled with the widespread availability of a serum antibody test to screen for HIV in 1985, led many states to initiate reporting of HIV infection in addition to AIDS case reporting.

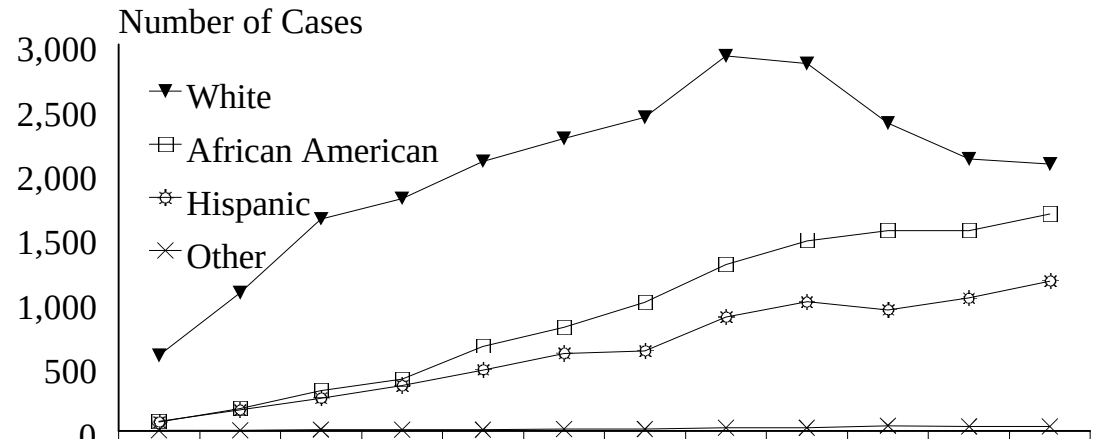
Why AIDS Case Reporting Is Not Enough: Effects of New Treatments

From a public health and epidemiologic perspective, the advantages of tracking and profiling HIV are significant, as HIV infection marks the beginning of the disease process rather than the end. In contrast, AIDS surveillance is triggered by events marking late-stage progression of disease. Due to the effect of new HIV treatments, those states and territories which rely on AIDS case surveillance information to target HIV prevention efforts will have a distorted picture of HIV-infected populations.

Using AIDS case reporting information to target prevention and service resources has been criticized because of the lag between infection and the development of the conditions used to diagnose AIDS. This lag was longest for people diagnosed under the case definition based on development of opportunistic infections (OIs), for at that time, OIs did not appear until eight to ten years after infection with HIV. The case definition shift in 1993 meant people were counted as AIDS cases earlier in the development of disease, and this change was expected to make AIDS slightly more reflective of the front end of the HIV epidemic. However, for reasons outlined in this paper, this shift in AIDS definition is still not detecting persons early enough in the disease process.

New triple combination therapies and protease inhibitors have become available which delay for an unknown amount of time the drop in T-cell counts which currently defines AIDS. As can be seen in Figure 1 below, the number of white adult and adolescent AIDS cases declined after 1992. The rise of similar African American cases also slowed, as did cases for Hispanics and for people of other racial or ethnic groups. Some of the change may be attributed to prevention efforts. However, it is also possible that in recent years fewer people have reached the point of having low enough T-cell counts to be diagnosed as AIDS cases, thus contributing to the decline of AIDS among whites and its slowing among African Americans. As the effect of the new therapies on HIV deaths has already been felt, with July 1997 estimates showing that Texas 1996 AIDS deaths will fall by at least 10% compared to the previous year, it is likely that a similar effect will be observed in AIDS case reporting.

AIDS Case Counts by Year of Diagnosis and Race/Ethnicity: Texas, 1985-1996



	85	86	87	88	89	90	91	92	93	94	95	96
White	585	1,071	1,645	1,803	2,091	2,269	2,431	2,910	2,850	2,387	2,109	2,068
African American	69	171	312	400	654	802	995	1,289	1,475	1,553	1,553	1,682
Hispanic	71	163	254	350	472	601	621	882	1,002	939	1,030	1,161
Other	2	3	9	6	8	14	12	21	21	39	33	33

Year of Diagnosis

* Adjusted for reporting delay; AIDS database updated through 9/22/97

Figure 3 AIDS cases by year of diagnosis, adjusted for reporting delay.

Unfortunately, different groups of the affected populations have varying degrees of access to these treatments, and the treatments are not equally successful with all patients. All of this means that overall case counts are expected to decline, although we have no indication that HIV infection is decreasing. Treatment breakthroughs mean the profile of those individuals who are diagnosed with AIDS, either through lack of treatment or treatment failure, will not be representative of the profile of people living with HIV infection as a whole. All of this points to a decreased role for AIDS case data in tracking HIV infection and targeting HIV prevention resources.

The Need for a Fully Functional System for Monitoring HIV Infection

Disease surveillance, the collection and analysis of disease reports, plays a vital role in public health, providing the information needed to identify, track, and respond to disease trends in an effective and timely manner. Nationally, statewide, and on a local level, the ability to protect and maintain the health of the community depends on the availability of accurate, reliable and complete data. Nowhere is this more true than with HIV.

What Can Good HIV Surveillance Provide?

If the public health system is to adequately respond to changes in the epidemic, making appropriate allocations of resources and targeting services and interventions to groups most in need, it is imperative that Texas have a *fully functioning* HIV reporting system in place. In this context, fully functioning means able to support **all** the functions listed below.

Timely Referrals to HIV Care and Services: Functional HIV reporting systems should ensure that services are provided to vulnerable individuals, in particular to those who might otherwise not receive these public health and personal health benefits until later in the course of their infection. Early entrance into care reduces or slows the development of disease, may lower the spread of infection in the community, and results in substantial health care savings for the individual and the community.

Accurate Minimum Estimate of Infected Persons: HIV disease reporting can be used in conjunction with AIDS case surveillance to provide an accurate estimate of the minimum number of persons known to be infected in a given area.

The Ability to Monitor Recent HIV Infection: HIV disease reporting should provide data regarding persons who acquired HIV recently, compared to data from reports of those already diagnosed with AIDS.

Evaluation of Prevention Interventions: A functional system of HIV disease reporting may also be used to target and evaluate specific HIV prevention interventions, such as the recommended procedures to reduce the risk of perinatal HIV transmission.

Accurate Epidemiologic Profiles for Community Planning: States conducting HIV reporting have presented HIV data together with AIDS surveillance data in their epidemiologic profiles for community planning. Community planning groups in areas without HIV reporting have expressed concern about the lack of data reflecting recent transmission patterns.

Assistance to Physicians and Public Health Professionals in Providing Disease Intervention Services: Confidential HIV disease reporting should enable public health professionals to assist physicians in locating and notifying patients who fail to return for their HIV test results and thus remain unaware of their infection. HIV disease reporting should also support voluntary partner notification efforts. The partner notification process increases the chances that women of childbearing age and others who do not perceive a personal risk for infection will become aware of their possible exposure to HIV. For those who are HIV-infected and pregnant, timely medical intervention can greatly reduce transmission of the virus to their newborns. Partner notification also allows targeted intervention for those at the highest risk of HIV disease - those exposed to the virus by a sex and/or needle-sharing partner. Those partners who are unaware of their infection will have the opportunity to access needed early intervention services much sooner only if they are provided information about their at-risk status. Uninfected partners can be supported in making behavioral decisions that will allow them to remain uninfected.

Epidemiologic Investigations/Supplemental Research Studies: Confidential HIV disease reporting should enable those in the public health system to conduct epidemiologic investigations of cases of special interest, including HIV-2 and cases of possible unusual modes of exposure.

Accurate Data for Funding Considerations: Confidential HIV disease reporting should lead to additional cases of AIDS being identified and should increase the amount of funding received by the state of Texas. Advances in treatment and the use of protease inhibitors has delayed the onset of AIDS diagnoses and may impact the level of funding for Texas. A strong confidential HIV reporting system will position Texas to benefit from likely shifts in funding formulas in the future (i.e., funding based upon HIV disease reports and not AIDS cases).

Although all the functions listed above are important, the bottom line is that reliable and accurate HIV infection data is the best basis for allocating and targeting funds within the state for HIV care and prevention services. As AIDS case data becomes increasingly less useful, current funding formulas will fail to recognize important shifts in disease burden that should drive the allocation of funds.

Who is Recommending and Using HIV Infection Monitoring?

In recognition of the importance of monitoring HIV infection, the CDC disseminated their *Strategic Plan for Prevention of Human Immunodeficiency Virus (HIV) Infection*, which called for "…all states and major cities to have in place confidential HIV infection reporting systems that are linked to medical, social and prevention services by 1995." Recently many expert and advocacy groups have developed recommendations for HIV infection reporting.

- The Council and State and Territorial Epidemiologists 1997 position statement recommends that "all states and territories should implement confidential HIV reporting by name from health care providers and laboratories based on methods that provide

accurate and representative data for all persons confidentially diagnosed with HIV infection."

- The Association of State and Territorial Health Officers (ASTHO) recommends "that all states undertake named HIV reporting. However, ASTHO opposes any federal mandate to collect the names of HIV positive persons."

- The National Alliance of State and Territorial AIDS Directors (NASTAD) has disseminated a October 1997 position statement recommending confidential HIV infection reporting by name.

- The National Association for People with AIDS (NAPWA) supports HIV reporting, although they oppose named systems of HIV surveillance.

Currently, 27 states mandate confidential HIV reporting by name for adults and children, and three states (Texas, Connecticut and Oregon) require confidential HIV reporting by name for children only. Two states, Maryland and Texas, have confidential Unique Identifier (UI) HIV reporting, although Maryland requires the reporting of names for symptomatic HIV infections. The remainder of the states have anonymous HIV reporting systems or no reporting systems for HIV infection.

The History of HIV Reporting in Texas

Texas recognized the importance of tracking HIV infection in 1987, when the Texas Legislature made HIV infection a reportable condition. Between September 1987 and December 1989, HIV infections were reportable by age and sex only. In 1989, the Texas Board of Health approved new regulations for reporting HIV infection. The data to be reported was changed to include: race/ethnicity, county of residence, date tested (date blood drawn), date of birth (month and year) and sex. Only initial or first-time diagnosis of HIV infections, if made by or under the standing orders of a physician, and based upon acceptable laboratory test results, were to be reported.

In 1992, realizing this HIV reporting system did not meet public health needs, TDH proposed a named HIV reporting system to the Texas Board of Health. At that time, some communities raised confidentiality concerns regarding named reporting. In response, TDH considered and adopted the current experimental numeric based UI system for HIV reporting.

The Mechanics of the Unique Identifier HIV Reporting System in Texas

How the Current System Operates

Reporting of confirmed HIV infections by unique identifier (UI) for adolescents and adults began in March, 1994.[1] The UI reporting system in Texas is a dual system, with both test providers and laboratories required to report the four pieces of information of the UI for each individual with a confirmed HIV infection:

- the last four digits of the social security number (SSN)
- month, day, and year of birth (DOB)
- a numeric code for sex
- a numeric code for race/ethnicity.

These elements were chosen because, in theory, they are enduringly and consistently associated with each person. Mathematical modeling has demonstrated that combinations of these four elements usually allow true unique identification of an individual's report, and thus allow detection of duplicate reports. In addition to the UI information, test type, test date, test result, the zip code, city, and county of residence of the infected individual, and the name and address of the provider/laboratory reporting the infection is also required. No information on risk behaviors is routinely collected on HIV reports.

The new system was implemented with little additional infrastructure, with the exception of two dedicated positions for HIV surveillance funded at local health departments in Dallas and Houston. The system is predominately a passive reporting system, relying on providers and laboratories to submit reports to local health authorities, who in turn report required information to the TDH. Reports may be submitted in either paper or electronic form.[2]

Once a report has been submitted to the central database, a second process begins. The report is examined for completeness of reporting elements. All electronic reports are added into the database, regardless of completeness of the UI. However, only those paper reports with two or more elements of the UI present are added to the database; starting in 1995, paper reports with three or more UI element missing were considered ineligible for entry, eliminating an estimated

[1]Confirmed HIV infections in children 12 years of age and younger are reported by name.

[2]A new electronic reporting system, STD/HIV AIDS Reporting System (SHARES), was introduced in key local and regional STD reporting sites in 1995. SHARES allows these programs to report both STDs and HIV via one integrated software system. Encrypted reports are submitted via diskette or electronic data transfer to the TDH central office at the beginning of each month.

7,000 private laboratory reports from the data.

Although a report will be accepted into the database if any of the UI elements are missing, reports with missing UI elements are excluded from HIV infection case counts, for the UI cannot be compared against other cases to check for duplication of report. For purposes of surveillance, a report without a complete UI must be discarded. If the report has all four elements of the UI, it is compared against other complete reports. Reports with matching UI are examined for date of test, and the report with the earlier date of test is maintained in the records, with the second report discarded as a duplicate case.

Finally, UIs for cases of HIV infection are compared against UIs in the AIDS database to remove from HIV analysis sets any HIV infection cases which appear to have already progressed to AIDS. If the UI system was performing optimally, we would lose very few reports to element incompleteness or to appearance in the AIDS registry, and show a duplication ratio close to 50%.

Limitation of UI System: Provides Epidemiologic Monitoring Information Only

It should be recognized that the TDH was aware at the time the UI system was adopted that it could not support some of the core functions outlined previously. When HIV infections are reported, only the UI of the patient is forwarded through the system. Our experience is that UI reports are exceedingly difficult to trace back through the infection reporting system. If follow-back for public health purposes is impeded, then the system can no longer support four of the eight core functions of an HIV surveillance system: *timely referrals to HIV care and services, assistance in providing disease intervention services, support for epidemiologic investigations/supplemental research studies,* and *support for AIDS case finding.*

In theory, the UI system should be able to provide epidemiologic data of acceptable quality, thus allowing the other four functions to be fulfilled, all of which hinge on complete and accurate reporting of known HIV infections. The system is, in effect, a *unifunctional* system, at best capable of providing only information for epidemiologic monitoring of HIV infection, and unable to systemically support patient referral and disease intervention services. This shortcoming was recognized but not resolved at the time of the system's design. However, because of the difficulty in following back incomplete infection reports using only a UI, the success of the UI reporting system in fulfilling the remaining surveillance functions is wholly dependent on providers and laboratories submitting *complete initial* reports.[3]

[3]Maryland, which also uses a UI system, requires providers to keep logs showing the name and UI for all HIV tests. This would allow the provider to supply additional information on cases. Maryland has not found this approach to be successful.

Evaluating the Performance of the UI System

Completeness of UI Reporting Elements Is Unacceptably Low

The performance of the UI system in its first three years has been poor. As Figure 2 shows, only **21%** of the estimated 32,094 HIV reports submitted between April 1994 and June 1997 have been counted as cases of HIV infection not believed to have progressed to AIDS.[4] The primary problem with the UI reporting system lies in the estimated 17,839 reports submitted with incomplete UI information. As Figure 3 shows, this means that **56%** of the reports submitted between April 1994 and June 1997 were missing at least one element of the UI.[5] By comparison, the proportions of reports eliminated as duplicates (**11%** of the estimated total) and as cases of infection which have already progressed to AIDS (**12%** of the estimated total) are small.

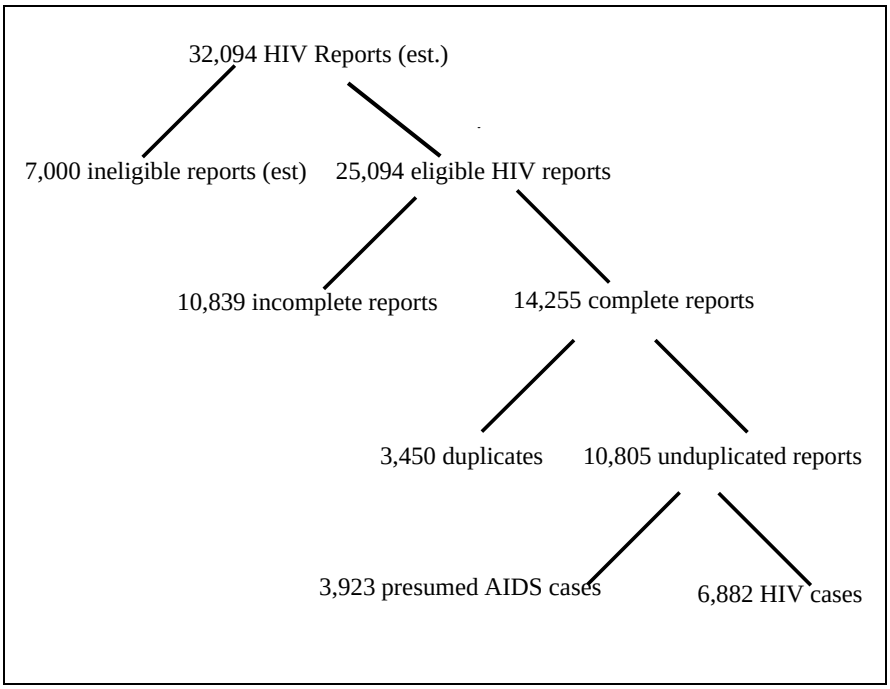


Figure 2: HIV Reporting Flowchart

When only the reports entered into the infection database are considered, the proportion of reports with complete UIs has improved over time. Figure 4 shows proportion of reports with complete UIs by date of test; these figures are not adjusted for reporting delay. The proportion of tests with complete UIs rose from about 30% for tests with test dates in the first six months of 1994

[4]These estimated totals and estimated number of incomplete reports referred to subsequently include the estimated 7,000 private laboratory reports eliminated from entry into the system due to gross incompleteness of UI.

[5]If only the reports entered into the system are considered, **57%** had at least one piece of UI information missing.

to around 60% in late 1994 and throughout 1995. Tests run in 1996 showed the proportion of completes rising from 64% among tests performed in the first quarter to approximately 70% complete for the third and fourth calendar quarter of that year.[6]

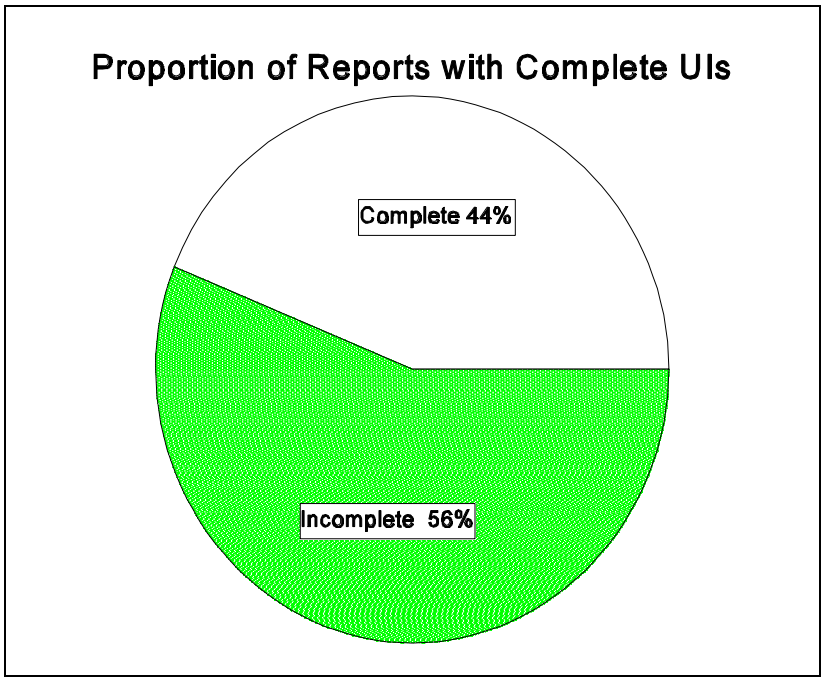


Figure 3: Estimated Proportion of HIV Reports Submitted from 4/94 - 6/97 with Complete UIs

This improvement in report completeness means that missing genders, birth dates, and race/ethnicity indicators have all but been eliminated. Missing social security numbers now make up almost all of the missing information, with 28% of the reports with test dates in 1996 missing SSN, as compared with 2% missing sex, 3% missing birth date, and 4% missing race/ethnicity.

Some of the increases in the proportion of complete reports are due to actual improvements in reporting. For example, the implementation of an updated laboratory form at TDH may partially account for the early upswing observed in early 1995, and the introduction of an electronic HIV reporting system for major public reporting facilities in 1996 explains some of the improvement in completeness seen in that year. However, as important as it is to note these improvements in reporting, the elimination of grossly incomplete reports from entry into the reporting database, which began in 1995, increased the proportion of complete reports by simply lowering the total volume of reports into the system. It is also important to note that the best performance of the system still allows about 30% of the reports received at TDH to be laid aside due to item incompleteness.

[6] 1997 tests are omitted from this analysis due the small numbers of tests in the database at this time; we have not yet received data on 1997 tests from the TDH lab. Until those reports are entered, any data on completeness are not representative.

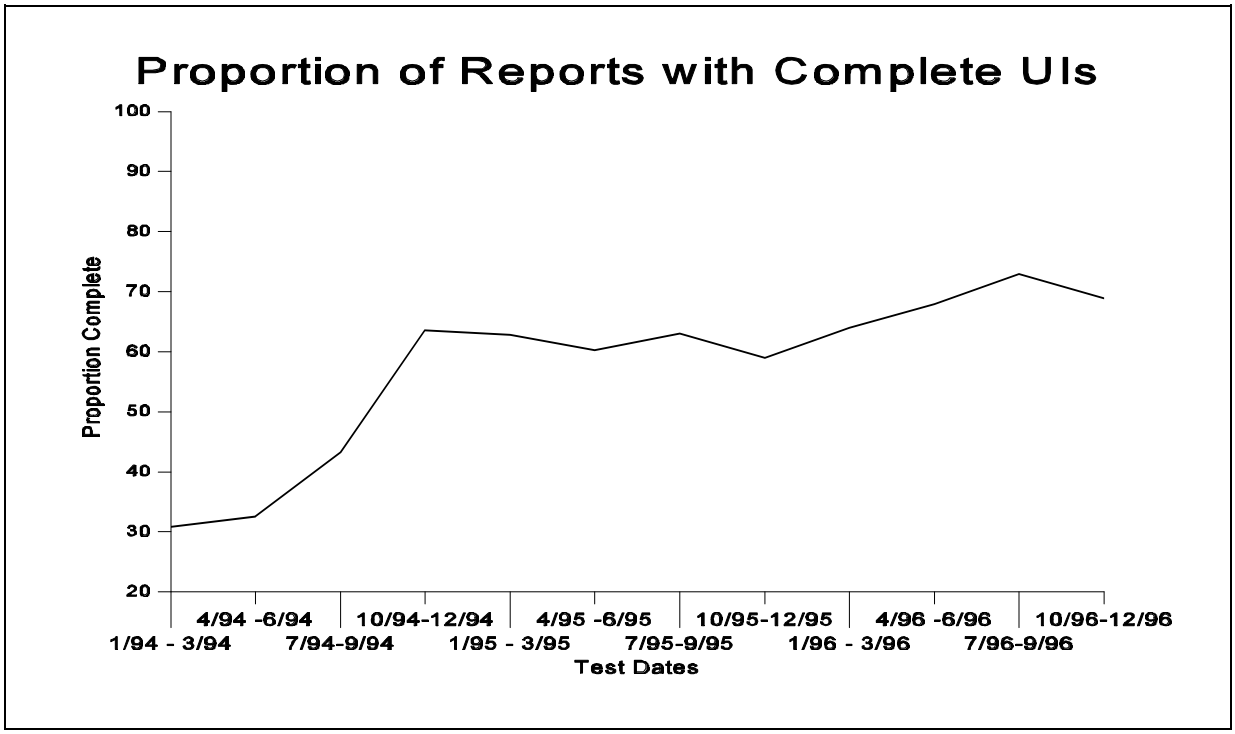


Figure 4: Changes in Proportion of Reports with Complete UIs

Limited Prospects for Improving Item Completeness through Surveillance System Follow Up

In terms of element completeness, the performance of the system is far below acceptable levels for surveillance purposes. If the current HIV reporting system is to provide valid, usable data, the proportion of complete reports must be increased dramatically. However, our experience suggests that using field follow up to complete reports submitted with an incomplete UI is not feasible.

In order to estimate the difficulty of tracing back reports, the TDH attempted to trace back a sample of reports from representative reporting sites in six areas of the state. The providers fully cooperated in this project. Only 60% of the complete case reports could be linked with a client/medical record at the source of report. Success was even more limited when only incomplete infection reports were considered: staff were able to match only 31% of all incomplete HIV reports to source records.[7] Once the records were located, they were examined to abstract missing case information on each report. Although almost all the missing information on sex and date of birth was easily recovered from the providers' case records, only 50% of the reports

[7] 40% of the successful locations used the UI elements only to find the desired record; the remainder relied on the combination of UI information with other information provided on the infection report, such as residential information or local identifiers.

missing information on race/ethnicity and 40% missing SSN were found to have this information available in the source reports. This experience suggests that field follow up to complete HIV reports would have limited success.

Current UI Reports Under-Represent Private Sources of Testing

The elimination of almost all private laboratory reports from entry into the system, necessitated by the gross lack of completeness of these reports, epitomizes the most basic limitations of these reporting data. They are incomplete in two important ways: the reports themselves contain missing elements, and the reports primarily represent infections detected through public sector testing. The low proportion of complete reports results in a significant artificial depression in the official HIV case counts for counties, regions, and the state as a whole. This depression can be illustrated by comparing the number of AIDS cases diagnosed in 1995 (5,010)[8] to the number of non-AIDS HIV cases with test dates in 1995 (2,195). Analysis of completeness of HIV reporting in Texas conducted by matching UIs constructed for cases in the AIDS registry to UIs in the HIV registry suggests that the current system is capturing only **25%** of all HIV infections. This is in contrast to the 85% - 90% reporting completeness typically reported for AIDS surveillance systems.

Further, the reports currently entering the system are not representative of HIV infection, for current reporting sources are overwhelmingly public providers of testing. For all reports received between March 1994 and June 1997, only 6% were submitted by private physicians and hospitals, and 4% submitted by private laboratories. The public sector sources, the TDH laboratory and local health departments, submit 77% of the reports currently in the system.[9] This distribution can be compared to the source of STD infection reports, which for Texas cases diagnosed in 1996 showed 46% of the reports coming from public sources, and 49% of the reports originating from private sources. As an HIV infection profile which is skewed towards the public sector is not representative of the epidemic as a whole, in terms of representativeness of reports, the performance of the HIV reporting system falls unacceptably short.

UI Elements Are Not Reported Consistently/Reliably

These two issues relate to the usefulness of reporting information. In this context, reliability and validity refer to the stability and accuracy of information as it flows through the system. Studies such as the field follow up described above and some analyses of information flowing through the HIV counseling and testing system (CTS) and laboratory data matching systems suggest that there are unacceptable numbers of reports in the infection database which do not reflect information in

[8]AIDS figures adjusted for reporting delay for cases reported through 2/13/97.

[9]The remaining 13% were submitted by CBOs, CTS sites, and freestanding clinics, some of which are private, some public.

the clients' records. There is also evidence that information on client race/ethnicity and sex is not consistently recorded/reported. For a system in which information on gender, ethnicity, and age are only ancillary data, this evidence would be disheartening. For a system such as Texas', which relies on these fields to make identification of cases, it destroys the very integrity of the data. If data are not accurate or at least reliable, then it is impossible to identify unique and duplicated cases, and counts of infection will be either over or underestimated in a way impossible to correct with statistical formulas.

Difficult to Eliminate Cases Already Progressed to AIDS

The differences in the information included in case reports of AIDS and HIV make it difficult to determine which reports of HIV infection represent cases which have progressed to AIDS. It is possible to generate UIs for most AIDS cases and remove cases of HIV which have matching UIs, thus creating an HIV database free of cases known to have progressed to AIDS. Unfortunately, the instability of the UI elements means that such a match can never ensure that all known AIDS cases are removed from the HIV data. As one of the primary purposes of HIV surveillance is to create a picture of the scope of HIV disease, especially newly acquired cases, a system which cannot easily distinguish between cases of HIV infection and AIDS is less useful than a system which would easily allow such a distinction.

Barriers to UI Reporting System Improvement

If the UI system is to function adequately as an epidemiologic monitoring tool, the barriers described below must be overcome.

Improving Ability of Private Laboratories to Report UI: From the very beginning of UI reporting, private (non-TDH supported) laboratories have had difficulty capturing, storing, and reporting UI information, with more than 85% of the reports in the first nine months of 1994 having incomplete UIs. Most private laboratories in Texas do not request information on SSN or race/ethnicity. They would also have to make costly changes to their data processing systems to capture, retrieve, and report the UI information. The TDH has no resources to underwrite the costs of these changes. Further, to ensure completeness of reporting items, the laboratories would either have to refuse to accept specimens from providers unless UI information was furnished, which is unlikely, or agree to accept the responsibility for calling providers to complete the UI information before passing the report on. This is even less likely, and would lead to increases in waiting times for results to be returned to tested clients. Although the latter activity is part of the UI reporting process in Maryland, it has had varying success in reducing incomplete submissions depending upon the laboratories' willingness to pursue the information and the providers' willingness and/or ability to provide it.

Enhancing Willingness of Providers to Report UIs and of Clients to Divulge It: Some providers and clients are unwilling to report UI information, particularly social security numbers, for fear that the information will be misused or because they do not trust the confidentiality of the information. Although their concerns are not supported by the excellent history of protecting confidential information by the public health surveillance system in this state, these perceptions are difficult to change.

***Increasing Local Health Department Participation In and Support of the UI System*:** Local health authorities have little incentive to support the UI system, beyond faithfully fulfilling their legal responsibility to report HIV. A recent survey of key providers indicated that local health department surveillance programs found the UI reporting system inflexible and difficult to work into their current surveillance practices and standards, and 90% of those surveyed would not recommend the UI system to states/territories considering use of the system for HIV surveillance. Furthermore, the UI system does not give them the information needed to assure linkage to services. Finally, public (and private) health providers are aware that UI reporting does not perform well in meeting its primary function (to provide epidemiologic data) and that they can do little in terms of follow up to improve the quality of reports without reallocating scare resources. All of these factors make it difficult for them to fully support the system and provide the resources (time, energy, person hours) necessary to improve the system and the data at a local level.

Conclusion: UI HIV Reporting Systems Are Not Fully-Functioning HIV Reporting Systems

The analysis of our current unique identifier HIV reporting system has shown that it does not provide us with reliable and accurate data on the number of persons infected with HIV infection in Texas. As a consequence we are unable to carry out informed planning for prevention programs and clinical and social services, and are unable to use our reporting system to appropriately allocate funds or other resources. As discussed earlier, this system also prevents health professionals from performing many core public health functions at the local health department level, such as linking clients to needed care and services and providing important partner notification assistance. With new treatments for HIV infection continually emerging and the consequent understanding that earlier identification and treatment can mean longer survival for the HIV infected person, having a system that can identify persons early in their disease is imperative. Likewise, such a system will best ensure that resources are allocated wisely so that treatment and other crucial services such as ongoing support for behavioral change are available where and when they are needed.

Although it does protect the confidentiality of infected individuals, the results of our evaluation of the current system indicates that the UI reporting system cannot be considered a satisfactory tool for monitoring HIV infection. Problems of completeness and reliability of UI elements and representativeness of reports (e.g., public vs. private sources of testing) are not easily solved.

Seeking to improve reporting, the TDH has undertaken consultations with local and regional health department surveillance staff and worked with the TDH laboratory to improve completeness and representativeness of HIV UI reporting. However, even with intensive infusions of resources, the system will never support all the functions expected of an infection monitoring system.

Before leaving this topic, however, we should note that the unsatisfactory performance of the UI system is not wholly attributable to the way the system was implemented in Texas. Maryland, the other state current using a UI system, instituted a reporting structure very different from Texas', with only laboratories charged with reporting HIV infections. Even with this difference, they report similar problems with reporting item completeness and completeness of reporting/representativeness. Other states have also considered and rejected non-named alternatives for reporting of HIV and CD4+ counts. In Connecticut, providers were unwilling to take on the added reporting responsibilities which a UI brings, while New York was unable to develop an acceptable non-named reporting system. After experimentation with non-named "uniform identifiers", New Jersey rejected this system in favor of named HIV reporting in 1992.